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ABSTRACT

The brief paper summarizes the final report of a federally funded project titled, "Ramps Are Not Enough: The Movement of Children with Mental Retardation from Institutional to Community-Based Care." The follow-up study of former residents (N=178) of New Hampshire's Laconia State School included an examination of residential and educational consequences of deinstitutionalization, four in-depth case studies, and an effort to trace the chronological relationship between federal and state policy and budgetary changes and the community living experiences of subjects. Among results were the following: on leaving the school, most residents returned to natural families, foster, or group homes; although ex-residents tended to stay in community placements an average of 3 to 4 years, almost half of the placements lasted less than 1 year and almost one-third of the subjects returned to the state school; although most children were originally placed in self-contained classrooms or schools many were later changed to less restrictive placements; about one-half of the sample changed educational placements once; vocational special education was received by relatively few children; and training in daily living skills or self-help skills was provided to most of the sample. (DB)

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ABSTRACT X
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DEINSTITUTIONALIZATION OF MINORS WITH MENTAL RETARDATION

The trend toward deinstitutionalization of residents of separate facilities, such as residential state schools, represents an effort to provide mentally retarded persons with access to richer experiences and a more "normal" life through participation in day-to-day community living. In order to realize this goal, policy makers, service providers, and parents must be concerned with the effects of deinstitutionalization—whether assimilation into the home community actually occurs or whether former residents of special schools continue to face alienation from the community as well as facing the problems endemic to daily community living. Information on the experiences of deinstitutionalized persons is needed in order to plan appropriate supportive services.

Ramps Are Not Enough: The Movement of Children with Mental Retardation from Institutional to Community-Based Care is a 219-page report of a follow-up study of former residents of New Hampshire's Laconia State School (LSS). The study included an examination of residential and educational consequences of deinstitutionalization, four in-depth case studies, and an effort to trace the chronological relationship between federal and state policy and budgetary changes and the community living experiences of the study's subjects.

SAMPLE

The sample included two groups. The primary sample consisted of those who had left the school before their 21st birthday ($n = 68$). For comparative purposes, a sample of residents who remained at the school past the age of 21 was drawn ($n = 110$). Those who remained at the school after their 21st birthday were, in general, more severely disabled. Potential subjects had to meet several study requirements. They must have been born between January 1, 1949, and June 30, 1985; resided at the school between January 1, 1970, and June 30, 1985; been located by the researchers; and provided informed consent to participate in the study.

METHOD

The study was guided by one primary question: What are the residential and educational consequences of deinstitutionalizing children with mental retardation? Data were collected to address a model of "communitization" variables affecting children. The model includes characteristics of the individual, family, and community; mandates and policies; and placement outcomes. The methods of data collection included review of clinical and school records and other archival data, and interviews with parents, case managers, service providers, and the school's ex-residents. The method of analysis was triangulation, a technique that applies multiple tools of measurement to multiple groups of informants. In addition to providing overall descriptive data, the researchers divided the primary sample into cohorts of residents who left the school during five 3-year-periods in order to trace changes over time.

RESULTS

During the period of study, public policies changed, the availability of services changed, and the technology for treating severely handicapped children changed. The researchers made an effort to relate their results to changes in federal and state policy and service availability.

Some of the results describing residential consequences are as follows:

- On leaving the school, most residents returned to their natural families or to foster or group homes. In recent years, they have been more likely to be placed in group homes.
- Ex-residents of the school tended to stay in their community placements an average of 3 to 4 years. However, almost half of the placements lasted 1 year or less, and in the early years of the study period, almost one-third of the subjects returned to the state school.

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- Of the community services used by the sample, therapeutic services were used most frequently, medical and habilitative services were used sporadically, and social and vocational or prevocational training services were used infrequently. In general, sample members who left the school after 1978 used services more frequently. The authors suggest that this is due to greater service availability.

The following highlights represent some of the results describing educational consequences of leaving LSS:

- The majority of children were placed in self-contained classrooms or schools when they first left LSS; however, nearly half later changed educational placements, and these changes were generally to less restrictive placements.
- Although slightly over one-half of the sample changed educational placements once, less than one-quarter changed placements again.
- Nearly 62% attended programs in the school districts in which they lived. The authors illustrate a trend toward in-district placements, which they attribute to policy changes.
- Vocational special education was received by relatively few children, although the average age of the sample (13 years) indicates that such training would be appropriate.
- Training in daily living skills or self-help skills was provided to most of the sample.

Descriptive data on the effects of deinstitutionalization on the families of former LSS students are also provided.

IMPLICATIONS

The changes associated with deinstitutionalization identified by the study are seen as generally positive. The authors conclude that education and related services have become more available in recent years. For example, the incidences in which children receive no educational program after leaving LSS have declined to zero, children are now more likely to receive education in their home districts, and case management is provided more frequently. However, the authors believe that issues of full social integration, appropriateness and accessibility of services, and the creation of truly family-like living arrangements remain to be solved. They expect that further improvement in the living conditions of deinstitutionalized persons will depend on the commitment of policy makers, professionals, and parents.

Ramps Are Not Enough: The Movement of Children with Mental Retardation from Institutional to Community-Based Care. June 1986. 275 pp. Bruce L. Mallory and Susan C. Herrick, University of New Hampshire. This project was supported by grants from the Central University Research Fund, University of New Hampshire, and the Spencer Foundation, Chicago, Illinois. Available for $.78 (microfiche) or $20.35 (hard copy), plus postage, from ERIC Document Reproduction Service, 3900 Wheeler Avenue, Alexandria, VA 22304 (1-800-227-3742). Order ED Number 274 118.

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RESEARCH & RESOURCES ON SPECIAL EDUCATION
THE COUNCIL FOR EXCEPTIONAL CHILDREN
1920 ASSOCIATION DRIVE, RESTON, VA 22091